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ABSTRACT

This U.S. General Accounting Office report discusses the Medicaid management controls needed to assure that mentally retarded residents of nursing homes receive the services they need to help them function independently. Medicaid's involvement with the retarded in institutions and nursing homes includes financing active treatment services, such as speech, occupational, and physical therapy; training in personal care skills; and training in community living skills. Medicaid services for the mentally retarded were reviewed in 15 nursing homes in Connecticut, Massachusetts, and Rhode Island, and similar reviews by the Health Care Financing Administration in Illinois and Indiana were analyzed. The report found that management controls were inadequate, plans of care did not adequately address active treatment, and inspections were inadequate. The General Accounting Office's recommendations to the Secretary of Health and Human Services and the comments from involved state agencies are provided. Recommendations included the revision of Medicaid regulations to require nursing homes to specifically address active treatment in plans of care for their retarded residents, and to require states to include a staff member trained in mental retardation on inspection of care teams. (JDD)

GAO

United States General Accounting Office

Report to the Secretary of Health and Human Services

April 1987

MEDICAID

Addressing the Needs of Mentally Retarded Nursing Home Residents

GAO

United States
General Accounting Office
Washington, D.C. 20548

Human Resources Division

B-226561

April 15, 1987

The Honorable Otis R. Bowen, M.D.
The Secretary of Health
and Human Services

Dear Mr. Secretary:

This report discusses the Medicaid management controls needed to assure that mentally retarded residents of nursing homes receive the services they need to help them function independently. We conducted this review to ascertain whether mentally retarded persons treated in nursing homes have the same access to needed services as their counterparts in facilities for the mentally retarded. This evaluation is part of our effort to assess access and quality-of-care issues related to Medicaid long-term care services.

This report contains recommendations to you in chapter 2. As you know, you are required by 31 U.S.C. 720 to submit a written statement on actions taken on these recommendations to the Senate Committee on Governmental Affairs and the House Committee on Government Operations not later than 60 days after the date of the report and to the House and Senate Committees on Appropriations with the agency's first request for appropriations made more than 60 days after the date of the report.

We will be sending copies of this report to the House and Senate committees having jurisdiction over the Medicaid program, the governors of the states discussed in the report, and other interested parties.

Sincerely yours,

Richard L. Fogel

Richard L. Fogel
Assistant Comptroller General

Executive Summary

Purpose

During the 1970's, attention was focused on the poor quality of care provided in state institutions for the mentally retarded. As states acted to reduce overcrowding and improve the quality of care in such institutions, the retarded were increasingly admitted to nursing homes. Little attention has been focused, however, on the quality of care provided to the approximately 140,000 retarded nursing home residents supported by Medicaid.

GAO reviewed Medicaid management controls to determine whether they adequately ensure that mentally retarded nursing home residents receive the services they need to help them function independently.

Background

Many services that retarded persons need are financed through Medicaid, a medical assistance program for the needy. Established as a partnership between federal and state governments, Medicaid finances care for the retarded in institutions and in nursing homes (i.e., skilled nursing facilities and intermediate care facilities).

In addition to meeting the medical needs of their residents, nursing homes are required by the Department of Health and Human Services (HHS) to provide services to their mentally retarded residents to help them function independently. Such services, referred to collectively as active treatment, include

- speech, occupational, and physical therapy;
- training in personal care skills, such as dressing, feeding, bathing; and
- training in community living skills, such as crossing streets, taking a bus, shopping, or preparing meals.

To see if nursing homes were meeting the active treatment needs of their retarded residents, GAO reviewed Medicaid services provided to the mentally retarded in 15 nursing homes in Connecticut, Massachusetts, and Rhode Island. In addition, the results of similar reviews HHS's Health Care Financing Administration had done in Illinois and Indiana in 1984 and 1985, respectively, were analyzed by GAO.

Results in Brief

Mentally retarded residents in Connecticut, Massachusetts, and Rhode Island nursing homes generally had not had their active treatment needs identified and met. These conditions existed because

- nursing homes were not part of the service delivery network for the retarded,
- nursing homes did not prepare written plans of care to assess the active treatment needs of their retarded residents and develop programs to meet those needs, and
- state inspectors were not determining whether retarded residents were receiving needed active treatment services.

Steps taken by the Health Care Financing Administration's Chicago regional office and the states of Indiana and Illinois to identify and correct similar problems found in those states provide a framework for action by other HHS offices and states to assess and meet the needs of retarded nursing home residents.

Principal Findings

Management Controls Are Inadequate

Medicaid regulations contain a series of controls to help ensure that the active treatment needs of individuals admitted to a facility for the mentally retarded are met. Among other things,

- written procedures must be established outlining the facility's role in the state's comprehensive program for the mentally retarded;
- written plans of care must be developed for each individual assessing his or her needs for active treatment services, describing programs to meet those needs, and establishing goals to measure progress; and
- state inspection teams must include at least one member who knows the problems and needs of mentally retarded residents.

Similar requirements do not, however, exist when a retarded person is admitted to a nursing home.

The Medicaid agencies in Connecticut, Rhode Island, and Massachusetts generally did not consult with the state retardation agency responsible for identifying and developing programs to meet the needs of the mentally retarded before authorizing nursing home admission for retarded persons. As a result, the retardation agencies in the three states were not aware of 1,477 of the 2,238 retarded nursing home residents GAO identified in the states.

Evaluations of 187 of the 1,477 residents identified 70 who might have benefited from one or more active treatment services. Only 4 of the 70 had received active treatment.

Similar problems were identified in Illinois and Indiana in 1984 and 1985, respectively. In Illinois, the Health Care Financing Administration identified 3,190 retarded nursing home residents. A random sample of 32 of the residents showed that none of their active treatment needs were being addressed. And in Indiana, about 4,000 retarded nursing home residents were said by the Administration to need active treatment services.

In response to the findings, both states established preadmission screening programs that require an evaluation by the retardation agency before a retarded person can be admitted to a nursing home. Both states also hired a consultant to assess the active treatment needs of the mentally retarded already in the states' nursing homes and develop programs to provide active treatment or placements in facilities for the mentally retarded where such services are provided.

Plans of Care Do Not Adequately Address Active Treatment

GAO reviewed the plans of care for 89 mentally retarded residents in 10 Connecticut, Rhode Island, and Massachusetts nursing homes. Of the 89 plans, 50 did not contain an evaluation of the residents' active treatment needs or indicate that the resident could not benefit from active treatment because of his or her medical condition. GAO did not evaluate the adequacy of the assessments performed for the 39 retarded residents whose plans of care contained an assessment.

HHS's reviews at four Illinois and two Indiana nursing homes identified similar deficiencies. In Illinois, HHS noted that 27 of the 32 plans of care reviewed either lacked a discussion of developmental and behavioral needs or were inadequate.

Inspections Are Inadequate

States are required to review the adequacy of the care provided to each nursing home resident at least annually. These inspections of care are the primary management control to ensure that nursing home residents' health, rehabilitative, and social needs are met. However, in the three states GAO visited, the inspections looked at nursing home procedures but did not assess the adequacy of services provided to retarded residents.

Inspection-of-care teams for intermediate care facilities for the mentally retarded included a mental retardation specialist and used a separate form to assess the adequacy of active treatment services. Connecticut, Rhode Island, and Massachusetts generally did not, however, include a staff member trained in mental retardation on review teams for nursing homes with retarded residents or use the special form for assessing active treatment. In its report on retarded residents in Illinois nursing homes, HHS recommended that the state (1) include a retardation specialist on the nursing home inspection team when retarded residents are present and (2) assess their needs using a form designed to evaluate retarded residents.

Recommendations

GAO recommends that the Secretary of HHS require those states that have not already done so to assess the active treatment needs of the mentally retarded currently in nursing homes and develop programs or alternative placements to meet those needs.

GAO also recommends that the Secretary of HHS revise Medicaid regulations to, among other things, require

- nursing homes to develop active treatment plans of care for their retarded residents,
- nursing home inspection-of-care teams to include a staff member trained in mental retardation when retarded residents are present,
- states to develop written procedures outlining the role of nursing homes in the state's program for the mentally retarded, and
- states to have the retardation agency assess the active treatment needs of the mentally retarded and the appropriateness of their nursing home admission.

Agency Comments

HHS, Massachusetts, and Connecticut generally agreed with our findings and recommendations and said that actions have been or will be taken to better ensure that mentally retarded nursing home residents receive needed active treatment services. Rhode Island officials generally disagreed with our findings and recommendations, but provided conflicting comments on whether a problem existed at the time of our review. (See pp. 29 to 37.)

Contents

Abbreviations

GAO	General Accounting Office
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services

Introduction

Federal and state governments finance care, through the Medicaid[1] program, for the mentally retarded living in institutions, community group homes, and nursing homes. For the last 15 years, advocates such as the Association for Retarded Citizens have argued that the care provided in large institutions for the retarded has been inadequate. Little attention, however, has been paid to retarded persons living in nursing homes. This report examines the services provided to Medicaid-supported mentally retarded residents in Connecticut, Indiana, Illinois, Massachusetts, and Rhode Island nursing homes.

What Is Mental Retardation?

The American Association on Mental Deficiency[2] defines mental retardation as subaverage general intelligence (IQ below 70) existing concurrently with deficiencies in adaptive behavior[3] appearing before age 18. The President's Committee on Mental Retardation estimated in 1975 that, in general, from 1 to 3 percent of the U.S. population is retarded. More recent studies also indicate that at least 1 percent of the population is retarded.

Retarded persons generally have more trouble feeding or dressing themselves, advancing in school, developing social relationships, or managing money than other individuals their age. To help them function as independently as possible, the retarded need such services as physical therapy, speech therapy, vocational activities, counseling, and training in activities of daily living.[4]

The American Association on Mental Deficiency adopted the following levels of mental retardation: borderline, mild, moderate, severe, and profound. These retardation levels can be correlated with functional characteristics, such as academic potential, vocational ability, and independence in activities of daily living, as table 1.1 shows.

[1]Medicaid, authorized under title XIX of the Social Security Act, is a federally aided, state-administered medical assistance program for low-income persons. Depending on a state's per capita income, the federal government pays from 50 to 78.6 percent of Medicaid costs for health services.

[2]An organization of physicians, educators, social workers, psychologists, psychiatrists, and other individuals interested in the welfare of the retarded and the study of the cause, treatment, and prevention of mental retardation.

[3]Adaptive behavior refers to the way individuals perform tasks expected of them at a given age. For young children, adaptive behaviors are dressing and eating with utensils. Older children are expected to go to school, advance in grade, and handle money. Adults are expected to hold a job and manage a household.

[4]Activities of daily living include personal care skills, such as bathing, dressing, eating, getting in and out of bed, getting around inside, and going to the bathroom.

Table 1.1: Correlations Between Retardation Levels and Performance

Classification criteria		Performance measures		
Retardation level	IQ range	Academic potential	Activities of daily living	Vocational ability
Borderline	65–70	6th grade	Independent	Competitive employment
Mild	50–70	4th grade	Independent with training	Employable
Moderate	35–55	1st grade	Trainable	Sheltered employment
Severe	20–40	Cannot read	Assistance needed	Special training
Profound	Under 20	None	Dependent	Limited

What Services Do Mentally Retarded Persons Need?

Retarded persons, like other persons, can grow and develop through education, training, and therapy to help them function in society. Such services are known collectively as active treatment or habilitation. Active treatment is generally defined as a series of programs and therapies to help the mentally retarded progress to their optimal level of independent functioning. Specifically, active treatment is the process of identifying a retarded person's need for services and implementing a plan of care that requires the individual to participate in specific programs and receive therapies. The next two paragraphs give some examples of the active treatment services mentally retarded persons can receive from educators, psychologists, social workers, speech therapists, vocational rehabilitation counselors, nurses, physicians, and other direct care personnel.

In the area of day programs, retarded persons can participate in training programs and vocational activities. Training programs include activities of daily living; community living skills (e.g., taking a bus, crossing streets, preparing food, and shopping); and communications skills. Vocational activities can include employment and workshops.

In the area of support services, retarded persons can receive therapies (e.g., physical, occupational, and speech/language); counseling (e.g., behavioral and interpersonal); transportation; and general health care.

Active treatment is based on the principle that learning is an interactive process in which behavioral skills are learned through stimulus-response chains that individuals experience. Through stimulus-response experiences, individuals relate a specific situation (stimulus) and behavior (response) to a subsequent condition (reward), so that after continued exposure to a given stimulus, an individual will exhibit a particular behavior when confronted with the same stimulus.

When these behavioral techniques are used, a wide range of skills relating to independence and self-care can be acquired by retarded persons for whom such skills might have seemed impossible. Research indicates that severely and even profoundly retarded individuals can learn and maintain valuable skills, such as choosing clothing, crossing streets, preparing a bowl of cereal, and identifying rest rooms.

Many mentally retarded persons work to meet their own basic living costs and either do not require special assistance or require it infrequently. Others, because of their level of retardation, require institutionalization.

Intermediate Care Facilities for the Mentally Retarded

In 1972 the Congress authorized states to use federal funding under the Medicaid program for intermediate care facilities for the mentally retarded.[1] The legislation relieved state agencies of part of the financial burden of operating large public institutions for the mentally retarded. To qualify for federal funding as an intermediate care facility for the mentally retarded, a facility must (1) have as its primary purpose the provision of health or rehabilitative services to mentally retarded persons, (2) meet standards established by the Secretary of Health and Human Services (HHS), and (3) provide "active treatment" to its residents. In fiscal year 1985, Medicaid spent $4.7 billion to care for about 146,000 residents in intermediate care facilities for the mentally retarded.

To qualify for federal financial participation, an intermediate care facility for the mentally retarded must provide active treatment. HHS regulations do not allow an intermediate care facility for the mentally retarded to admit retarded individuals unless their needs can be met by the facility or through contracts with another provider. HHS can disallow federal funding when it finds that an intermediate care facility for the mentally retarded has not provided active treatment. For example, HHS disallowed about $2.8 million in federal financial participation to two state-operated intermediate care facilities for the mentally retarded in Connecticut in 1983 and 1984 because active treatment was not being provided.

[1]An institution that provides health-related services to mentally retarded persons. These facilities also provide training in personal care and community living skills, prevocational activities, counseling, etc., to help the residents become as independent as possible

Many large public intermediate care facilities for the mentally retarded have had a hard time achieving compliance with HHS standards, particularly those relating to the physical facility. During the 1970's, advocates, such as the Association for Retarded Citizens, filed numerous lawsuits on behalf of retarded residents in state institutions claiming poor quality of care and living conditions. Because of these suits, states agreed to improve the services for retarded persons. According to a Health Care Financing Administration (HCFA) official, 30 states, including Massachusetts, Connecticut, and Rhode Island, were involved in at least one consent decree[6] covering residents in state-operated intermediate care facilities for the mentally retarded.

Attention continues to focus on conditions in large state-operated intermediate care facilities for the mentally retarded. An April 1985 staff report from the Subcommittee on the Handicapped, Senate Committee on Labor and Human Resources, and the Subcommittee on Labor, Health and Human Services, Senate Committee on Appropriations, identified significant quality-of-care deficiencies in state institutions.

Retarded Residents in Other Nursing Homes

One method for reducing overcrowding in large state-operated intermediate care facilities for the mentally retarded has been placing the retarded in other Medicaid-certified nursing homes (skilled nursing facilities[7] and intermediate care facilities[8]). An estimated 140,000 mentally retarded persons were in nursing homes in 1985, according to HCFA. Medicaid spent about $12 billion in 1985 to provide nursing home services to almost 1.4 million persons.

According to HHS, placing a mentally retarded person in a nursing home is appropriate if the resident's primary need for care is medical. An October 1982 supplement to HCFA's State Medicaid Manual states that:

[6]Consent decrees resulted from lawsuits filed on behalf of retarded citizens in state institutions. The result of the decrees was that the states and retarded citizens' organizations resolved that the states would provide specific services.

[7]A skilled nursing facility is a nursing home that provides 24-hour nursing or other services pursuant to a physician's orders. Such services, provided under the supervision of registered professionals (nurse, physical therapist, speech pathologist), include intravenous or intramuscular injections, intravenous feeding, insertion of catheters, ultrasound therapy, and heat treatments.

[8]An intermediate care facility is an institution that provides health-related care and services to individuals who do not require 24-hour nursing care, but who because of their mental or physical conditions, require care in addition to room and board dressing or bathing, routine care of incontinence, administration of oral medications, eye drops, etc.

"When the primary needs of retarded persons in nursing homes are medical, their developmental [active treatment] needs must still be met by the facility in the context of the individual's overall physical condition."

Under HHS regulations, a nursing home should not admit a person unless it is able to provide needed services, including active treatment, either directly or under an arrangement with an outside source.

Because active treatment services are not a separate service under title XIX, they, like most other services provided by a nursing home, are paid through an all-inclusive per diem payment. States use various methods to set per diem payments, ranging from a retrospective, reasonable cost reimbursement system, under which nursing homes are reimbursed for the actual allowable costs they incur, to a prospective payment system, under which per diem rates are set in advance and the nursing home may be permitted to keep all or part of the difference between the rate and actual costs (unless the nursing home's costs are more than the prospective payment, in which case it suffers a loss). Under both payment methods, the actual costs incurred by the nursing home in providing services, including any costs incurred to provide active treatment services to the mentally retarded, are factored into the rate-setting process.

Although active treatment costs vary depending on the services provided, they typically range from $4,500 to $14,000 per year, according to state retardation officials in Massachusetts, Rhode Island, and Connecticut. According to Medicaid officials, Medicaid paid an average of $15,620 a year for nursing home care in the three states.

How Does HCFA Ensure That Medicaid Nursing Home Recipients Receive Needed Care?

HCFA relies on state inspection agencies to ensure that nursing home residents receive needed care. States must inspect intermediate care facilities for the mentally retarded and other nursing homes at least annually and certify to HCFA that they meet Medicaid requirements.

Part of the inspection process concentrates on the facility and its compliance with specific Medicaid standards, such as the existence of written policies and procedures to (1) protect residents' safety, (2) ensure that nursing services are provided, or (3) dispense medication. The facility inspection also emphasizes the number and qualifications of medical and nursing staffs. According to Medicaid regulations, states must also conduct an annual inspection of care at each intermediate care facility for the mentally retarded and nursing home to ensure that adequate services are provided to nursing home residents. To determine the

adequacy of services provided, an inspection-of-care team, consisting of a physician or nurse and social worker, reviews medical records, residents' plans of care, nurses' notes, social service staff notes, and other documentation in the resident's file. The team also observes each resident for cleanliness, absence of bed sores, malnutrition, and apparent maintenance of maximum physical, mental, and psychosocial function. Inspection-of-care teams must also determine (1) if a resident's health, rehabilitative, and social needs can be met through an alternative institutional or noninstitutional setting and (2) if the resident needs any service that the intermediate care facility for the mentally retarded or the nursing home cannot furnish.

Inspection-of-care teams prepare a report containing observations, conclusions, and recommendations concerning the adequacy, appropriateness, and quality of all services provided in the nursing home.

Objectives, Scope, and Methodology

The objective of our review was to determine whether management controls established by HCFA and the states adequately ensure that retarded Medicaid nursing home residents who could benefit from active treatment services receive such services. Specifically, we wanted to find out whether

- adequate coordination existed between nursing homes, state Medicaid agencies, and state retardation agencies;
- plans of care for retarded residents addressed their active treatment needs;
- inspections of care identified weaknesses in the plans of care and services provided; and
- residents had active treatment needs that were not being met.

We performed work at HCFA's central office in Baltimore, at the HCFA regional office in Boston, and at state agencies in Connecticut, Rhode Island, and Massachusetts responsible for administering the states' Medicaid and mental retardation programs. In addition, we contacted officials from HCFA's Chicago regional office and the state mental health agency in Indiana to discuss the results of similar analyses HCFA completed in Indiana and Illinois.

We judgmentally selected 15 nursing homes to visit in Connecticut, Massachusetts, and Rhode Island so that

- each state was represented,

- nursing homes of various sizes (number of beds) were included,
- nursing homes with both a relatively large and a small number of mentally retarded residents were included, and
- nursing homes having both mentally retarded residents who were monitored by the state's retardation agency and residents who were not monitored were included.

Where feasible, our visits were scheduled to coincide with an inspection of care conducted by the state. At three of the nursing homes, we accompanied state retardation agency personnel on visits to the nursing homes and did not perform detailed work at the facility. Access-to-records problems that could not be resolved before our visits limited our work at two other facilities. The facilities visited are listed in appendix I.

To determine whether plans of care for retarded nursing home residents addressed active treatment needs, we

- compared the plan-of-care requirements relating to active treatment in intermediate care facilities for the mentally retarded to corresponding requirements for other nursing homes and
- reviewed the plans of care for 89 retarded residents in 10 of the 15 nursing homes visited to determine whether they contained an assessment of the residents' active treatment needs.

To determine whether nursing home inspections of care were identifying weaknesses in retarded residents' plans of care or ensuring that services were provided, we

- compared the inspection-of-care requirements for intermediate care facilities for the mentally retarded to those for other nursing homes;
- interviewed HCFA officials, state inspectors, and state Medicaid officials to find out whether the inspections of care addressed the needs of the retarded;
- observed inspections of care at 8 of the 15 nursing homes visited and at 2 intermediate care facilities for the mentally retarded; and
- reviewed the inspection-of-care reports for retarded residents in the 15 nursing homes visited.

To determine whether adequate coordination existed between nursing homes and the state Medicaid and retardation agencies, we

- screened 1985 inspection-of-care reports for the 16,310 Medicaid-supported nursing home residents in Connecticut and the 6,810

residents in Rhode Island and summary inspection-of-care data for 27,700 of the 40,000 Medicaid-supported nursing home residents in Massachusetts to identify those with a primary or secondary diagnosis of mental retardation;

- compared those residents identified as retarded to records maintained by the state retardation agencies in the three states to find out whether the agency was aware of and had assessed the active treatment needs of those residents;
- interviewed officials from the state Medicaid and retardation agencies and HCFA to find out the agencies' roles in providing services for the mentally retarded; and
- compared policies, regulations, and procedures to find out whether nursing homes were included in the states' retardation service delivery networks.

To determine whether retarded nursing home residents who were not receiving active treatment services needed such services, we

- obtained an assessment of the active treatment needs of 90 retarded residents not receiving active treatment from the retardation agency at four Connecticut and six Massachusetts nursing homes visited from HCFA's assistant regional commissioner for health standards and quality,
- determined whether the Connecticut and Massachusetts nursing homes were providing the needed services,
- obtained an assessment of the active treatment needs of 97 retarded nursing home residents from the Rhode Island state retardation agency, and
- reviewed reports and correspondence and interviewed HCFA and state officials about assessments of active treatment needs of retarded nursing home residents of Indiana and Illinois.

Based on the extent of the problems in meeting mentally retarded nursing home residents' active treatment needs found during our survey work in Connecticut, Rhode Island, and Massachusetts and in HCFA's analyses in Indiana and Illinois, we decided to report on the program control weaknesses that have permitted such conditions to exist rather than expand our work to other states.

For two major reasons, we did not estimate how Medicaid costs might be affected if active treatment were provided to retarded nursing home residents who want and need such services. First, it would have required a detailed assessment of each retarded resident's service needs

and desire for services. Second, because active treatment is not a separately reimbursable Medicaid service, it would have required complex analysis of the Medicaid nursing home payment systems in each state.

Our work was done between January 1985 and November 1986 and, except as noted above, was done in accordance with generally accepted government auditing standards.

Active Treatment Needs of Retarded Residents in Nursing Homes Should Be Identified and Needed Services Provided

The active treatment needs of retarded residents in Connecticut, Massachusetts, and Rhode Island nursing homes were generally not being identified and needed services were not provided because:

- State Medicaid agencies were not required to consult with the state retardation agency when a retarded individual was admitted to a nursing home for medical treatment.
- Medicaid plan-of-care guidelines for nursing homes do not specifically address active treatment for retarded residents.
- Medicaid guidelines for annual inspections of care for nursing home residents did not result in an evaluation of the adequacy of the plans of care.

At our request, HCFA evaluated the active treatment needs of a sample of 90 retarded residents in Connecticut and Massachusetts nursing homes who were not receiving active treatment. HCFA determined that about 67 percent might have benefited from active treatment day programs or support services. The Rhode Island retardation agency assessed the active treatment needs of 97 retarded nursing home residents it had previously been unaware of and identified 10 who needed and wanted active treatment day programs. Recent studies in Indiana and Illinois indicated that most retarded nursing home residents in those states could benefit from active treatment and that most would be more appropriately placed in an intermediate care facility for the mentally retarded.

Retardation Agency Should Be Notified When Retarded Are Admitted to Nursing Homes

Because nursing homes are not part of the retardation service network in Connecticut, Massachusetts, and Rhode Island, the state retardation agencies were generally not aware when retarded individuals were admitted to nursing homes. As a result, about 66 percent of the retarded nursing home residents in the three states were admitted to the nursing home without the retardation agencies' assessment of their active treatment needs.

Medicaid regulations require that intermediate care facilities for the mentally retarded have written procedures outlining the role of the facility in the state's comprehensive program for the mentally retarded. In the three states visited, intermediate care facilities for the mentally retarded were operated directly by the state retardation agency or under contract to the agency. As a result, the state retardation agency was aware of and could monitor the services provided to residents in intermediate care facilities for the mentally retarded.

Other nursing homes, however, were not part of the service delivery network for the retarded. The state Medicaid agencies were generally consulting the retardation agency only when retarded individuals were admitted to nursing homes because of their retardation rather than medical problems. The retardation agency was generally aware of a retarded individual's admission only if the agency had previously been providing services to the individual in an intermediate care facility for the mentally retarded or in the community.

The retardation agencies in Connecticut, Massachusetts, and Rhode Island were aware of only 761 of the 2,238 retarded nursing home residents we identified in their states. They had not assessed, or determined whether a multidisciplinary team such as the Association for Retarded Citizens had assessed, the active treatment needs of the other 1,477 (66 percent) retarded residents. Table 2.1 shows the number of mentally retarded identified in each state's nursing homes.

Table 2.1: Mentally Retarded Residents in Connecticut, Massachusetts, and Rhode Island Nursing Homes

State	Number of nursing home residents	Number of retarded residents	Residents not assessed by retardation agency
Connecticut	16,310	979	437
Massachusetts	27,726[a]	1,046[a]	909
Rhode Island	6,812	213	131
Total	**50,848**	**2,238**	**1,477**

[a]Data were not available on about 12,000 other nursing home residents in Massachusetts

We identified 122 nursing homes in Connecticut, 58 in Massachusetts, and 54 in Rhode Island where retardation agencies monitored and provided active treatment to some residents, but did not know about other retarded residents living in the same homes. For example:

- A nursing home housed eight retarded residents ranging in age from 46 to 79. The three residents monitored by the retardation agency attended day programs for the elderly, while the other five retarded residents not being monitored did not have their need for day programs assessed.
- A nursing home housed 18 retarded residents. All 17 consent decree class members, ranging in age from 49 to 84, received day programs. A 33-year-old retarded resident, not monitored by the retardation agency, did not have his need for day programs assessed.

HCFA Should Require Nursing Homes to Address Active Treatment in Plans of Care

Although the state Medicaid manual requires that retarded nursing home residents' active treatment needs be met, HCFA does not require nursing homes to develop a plan of care to meet them. In contrast, HCFA requires a detailed plan of care addressing active treatment services for individuals admitted to intermediate care facilities for the mentally retarded.

An integral part of the active treatment process is identifying the skills individuals need to help them reach their greatest level of independence. Specific measurable goals must be established and appropriate services provided. To accomplish this, a multidisciplinary team (nurse, psychologist, mental retardation specialist, doctor, resident, family, etc.) evaluates each individual and develops a plan of care, similar in characteristics to the following example:

- Identify the resident's strengths and weaknesses, such as good health but limited academic skills.
- Establish specific, measurable goals, such as the ability to recognize names and body parts.
- Identify services needed to meet the goals, such as a small group activity where names are paired with pictures.
- Define criteria to assess goal achievement, such as pointing to his/her own name when presented in groups of three names.

HCFA requires that a plan of care, containing all the elements described above, be developed for each retarded individual admitted to an intermediate care facility for the mentally retarded. The plan-of-care evaluations are generally coordinated by the state retardation agency.

Medicaid regulations also require a written plan of care for each resident admitted to a nursing home, but unlike the requirements for intermediate care facilities for the mentally retarded, the regulations do not address active treatment for the mentally retarded. To determine whether plans of care addressed retarded residents' active treatment needs, we reviewed 89 plans of care from 10 of the nursing homes visited. Of the 89 plans, 50 (56 percent) did not contain any evaluation of the residents' active treatment needs or indicate that the residents could not benefit from active treatment services. The other plans of care contained some evidence that residents' needs for specific services were evaluated. Of the 39 residents whose plans of care had some assessment of active treatment needs, 13 were monitored by the state retardation agency. We did not evaluate the adequacy of the assessments performed for the 39 retarded residents.

Nursing Home Inspections of Care Should Address Retarded Residents' Active Treatment Needs

Inspections of care are the primary program control to determine whether nursing home residents' health, rehabilitative, and social needs are met. The inspections of care, however, were not adequate to determine whether the active treatment needs of retarded nursing home residents were met because they (1) were not performed by persons trained in mental retardation, (2) did not determine whether the active treatment needs of the mentally retarded had been identified, and (3) did not determine whether the services available in the nursing home were adequate to meet residents' treatment needs.

Medicaid regulations require that the inspection-of-care team for an intermediate care facility for the mentally retarded include at least one member who knows the problems and needs of mentally retarded individuals and that the team determine whether each recipient is receiving active treatment. The regulations do not, however, contain similar requirements to assess the active treatment provided to retarded residents in other nursing homes.

In each of the states we visited, the inspection-of-care teams for intermediate care facilities for the mentally retarded included a mental retardation specialist and used a separate form to assess the adequacy of the active treatment services provided to the mentally retarded. The states generally did not include a mental retardation specialist or staff member trained in assessing the needs of the mentally retarded on the inspection team for other nursing homes or complete a form assessing the active treatment services provided to the nursing homes' retarded residents.

For example, the inspection teams for a Massachusetts nursing home we visited, where over 50 percent of residents were retarded, did not include a staff member trained in assessing the needs of the mentally retarded. HCFA regional office officials responsible for the inspections of care said that by not including inspectors experienced in assessing the needs of the retarded, the state agency limits its ability to evaluate the adequacy of services received or identify additional services needed by retarded residents.

The inspection agency has data indicating the number of retarded residents in the nursing home before the inspection of care is conducted. In the states we reviewed, the inspection agency sends each nursing home a preinspection questionnaire to obtain basic information about the nursing home and its residents. In many cases, the questionnaire responses indicate the number of retarded persons living in the nursing home. These data could be used to determine the makeup of the survey

team, particularly whether a retardation specialist should be on the team. State officials said the staff trained in mental retardation inspect only intermediate care facilities for the mentally retarded.

The inspections of care we observed at eight nursing homes were generally process oriented. The inspectors determined whether the plans of care were prepared and signed by a physician, but did not address the plans' adequacy or content. As discussed on page 20, 50 of the 89 plans of care we reviewed contained no assessment of the retarded residents' active treatment needs. Nor did the inspection-of-care forms for the residents identify any deficiencies in the plans of care.

Medicaid regulations require the inspection-of-care team to determine whether the services available in a nursing home are adequate to meet each resident's treatment needs. Other Medicaid regulations require that intermediate care facilities have written policies and procedures that ensure that the nursing home admits only individuals whose needs can be met by the nursing home itself, through community resources, or through other providers affiliated with or under contract to the nursing home. Under the regulations, the mentally retarded who are placed in nursing homes that are not capable of addressing the developmental needs of the mentally retarded are inappropriately placed, and federal funding for their care is not allowable.

Because the inspection-of-care teams were not addressing the adequacy or content of plans of care for mentally retarded nursing home residents, they could not determine whether the services available in the home were adequate to meet the residents' active treatment needs.

Many Retarded Nursing Home Residents Could Benefit From Active Treatment

Evaluations of the active treatment needs of 187 of the retarded nursing home residents previously unknown to state retardation officials identified 70 residents who could have benefited from one or more active treatment services. Only 4 of the 70 were receiving the needed services. Retardation agency officials in Massachusetts and Connecticut indicated that most of the retarded nursing home residents they were monitoring needed active treatment services more than medical care.

Not all retarded nursing home residents can benefit from active treatment; residents may have medical needs that preclude their participation in active treatment programs. We therefore asked HCFA staff trained in mental retardation to review inspection-of-care forms from four Connecticut and six Massachusetts nursing homes we visited to identify

needed services. We attempted to obtain a similar determination for the residents in the three Rhode Island nursing homes visited, but the data were insufficient for HCFA staff to evaluate active treatment needs. After we gave the Rhode Island retardation agency a list of retarded nursing home residents in the state that they were not monitoring, they assessed their active treatment needs. For the residents identified as needing services, we determined whether the services were being provided.

The forms for Connecticut and Massachusetts did not include sufficient data to determine the specific services residents needed but provided enough information to indicate activities or programs that might help the residents. The forms varied by state, but generally included data on diagnoses, medications, age, physical status, mental status, and socialization patterns. Physical status information described residents' functional abilities in the activities of daily living; speech, hearing, and vision problems; and therapies received or needed. Frequently, sections on needed services were not completed. Mental status described whether residents were alert, disoriented, confused, depressed, or had behavioral problems. Socialization patterns discussed how residents interacted with the staff and whether they participated in nursing home or outside activities. A comments section was also available.

Of the 90 residents reviewed, HCFA identified 60 (67 percent) who might have benefited from active treatment. None of the residents were receiving active treatment services.

The Rhode Island retardation agency staff assessed and reached conclusions on the active treatment day program needs of 97 retarded nursing home residents who needed such an assessment. According to information provided by the agency in August 1986, 10 residents needed and wanted day programs, and the retardation agency had begun delivering the needed services to 4 of them. Of the remaining 87 retarded residents, 25 did not want active treatment services, 44 could not benefit from active treatment because of their medical condition, and 18 were inappropriately diagnosed as retarded.[1] The retardation agency did not perform a detailed multidisciplinary evaluation of the residents and did not evaluate their need for support services, such as behavioral counseling and physical, speech, and occupational therapy.

[1]The diagnoses were questioned because they were made by psychiatric facilities that use different criteria (an IQ of 79 or below) to define mental retardation than the retardation agency (an IQ of 70 or below as recommended by the American Association of Mental Deficiency)

Table 2.2 provides details of the HCFA and Rhode Island assessments.

Table 2.2: Active Treatment Needs of Retarded Nursing Home Residents Not Monitored by the State Retardation Agency

	Connecticut[a]	Massachusetts[a]	Rhode Island[b]
Residents assessed	23	67	97
Services needed:			
Day programs	0	7	10
Physical therapy	2	12	[c]
Speech therapy	3	1	[c]
Occupational therapy	0	5	[c]
Behavioral counseling	6	35	[c]
Total	**8[d]**	**52[d]**	**10**

[a]Needs assessed by HCFA

[b]Needs assessed by Rhode Island retardation agency

[c]These services were not specifically identified in the assessment

[d]Some residents needed more than one service

According to retardation agency officials from Massachusetts and Connecticut, most of the retarded nursing home residents they monitor have a greater need for active treatment services than medical care and might be more appropriately placed in an intermediate care facility for the mentally retarded if such facilities were available.

Similar Problems Identified in Indiana and Illinois

HCFA studies in Illinois (1984) and Indiana (1985) identified serious deficiencies in the services provided to the mentally retarded in those states' nursing homes and recommended that the states determine whether the residents' needs could be better met in another facility. In August 1986, HCFA revised its State Medicaid Manual to include more specific guidance for evaluating the appropriateness of nursing home placement for retarded persons.

Illinois

According to HCFA's Medicaid program coordinator for Illinois, HCFA staff identified 3,190 mentally retarded residents in Illinois nursing homes in December 1983. HCFA medical professionals later visited four nursing homes and reviewed the services provided to 32 randomly selected retarded residents. In a May 10, 1984, letter to the director of the state Medicaid agency, the HCFA regional administrator stated that the study indicated that serious problems existed in the placement, monitoring, and inspection of care of mentally retarded persons placed in nursing homes. He said that none of the 32 residents reviewed had had their

special active treatment needs for their developmental and behavioral disabilities met by the nursing homes. He went on to say that the facilities were not adequately staffed with appropriately trained health professionals to plan and care for the needs of the mentally retarded residents.

According to the study report, plans of care relating to the developmental and behavioral needs of 27 of the 32 retarded residents sampled were lacking or inadequate. Nearly all plans of care were, the report stated, lacking objective measurable goals, and residents did not regularly participate in an individualized plan of care designed to meet their special needs. The study report went on to say that the fact that the residents' active treatment needs were not being met could be construed as a violation of their rights.

Among other things, the study recommended that the state

- reevaluate residents in nursing homes to determine whether their active treatment needs could be better met in an intermediate care facility for the mentally retarded or other setting,
- complete an interdisciplinary evaluation of retarded residents before or at the time an individual is placed in a nursing home,
- ensure that retarded individuals placed in nursing homes receive appropriate care to meet their special developmental and behavioral needs,
- revise its inspection-of-care procedures to use a form designed to evaluate mentally retarded residents when conducting the inspections at nursing homes that have retarded residents, and
- include a qualified mental retardation professional on the inspection-of-care team for nursing homes with mentally retarded residents.

According to the HCFA Medicaid program coordinator for Illinois, the state hired a consulting firm to develop a plan of correction. The coordinator said that Illinois has implemented a comprehensive screening program under which the mental retardation agency must participate in decisions to admit mentally retarded persons to nursing homes. The state is also converting some nursing homes to intermediate care facilities for the mentally retarded to better meet the active treatment needs of the retarded.

Indiana

According to a retardation official from Indiana's department of mental health, Indiana was in jeopardy of losing federal Medicaid funding for retarded residents in the state's nursing homes after HCFA found in

March 1985 that 4,000 retarded residents had not had their active treatment needs identified and were not receiving appropriate services. HCFA's report was based in part on a June 1983 report commissioned by the state retardation and Medicaid agencies that concluded that 1,824 residents with a primary diagnosis of mental retardation were inappropriately placed in the state's nursing homes.

HCFA's report noted that, in order to identify and better meet the needs of the mentally retarded, Indiana enacted legislation that requires that each retarded Medicaid recipient receive a diagnostic assessment from the state's retardation agency and be assigned to a case manager from the agency. The Medicaid agency continues to make the level-of-care determinations and placement decisions based on evaluative recommendations received from the retardation agency. According to a state retardation official, in the first year after a prescreening program was established, 11 retarded persons were admitted to Indiana nursing homes compared to 125 the prior year.

In a March 1986 report on its March 1985 review, HCFA recommended ongoing coordination between the state retardation and Medicaid agencies to ensure that Indiana's plan to develop appropriate programs for the mentally retarded was completed as scheduled. The report also said that the Medicaid agency should ensure that

- retarded nursing home residents are appropriately placed,
- the active treatment needs of the retarded are met regardless of whether they are in an intermediate care facility for the mentally retarded or a nursing home,
- the cost of day treatment programs provided to nursing home residents is covered as part of nursing home per diem, and
- residents who receive day treatment from an outside source receive follow-up active treatment in the nursing home.

In response to the legislation and HCFA's study, the Indiana retardation and Medicaid agencies entered into an interagency agreement to facilitate an assessment of all mentally retarded residents currently in the state's nursing homes. According to a state retardation specialist, a consultant was hired to assess the 4,000 retarded nursing home residents. She said that 2,375 assessments had been completed by July 1986 and that an additional 1,500 would be done by the end of 1986. Assessments of retarded residents in skilled nursing facilities will then be conducted, she said.

In a June 16, 1986, letter to HCFA's associate regional administrator, the head of the state Medicaid agency said that it appears that only about 330 of the 2,247 retarded residents assessed as of that date would require continued nursing home placement. He said that the overwhelming majority of those assessed can likely be moved to smaller, less restrictive, more active treatment oriented settings as such facilities become available.

In a July 2, 1986, letter, the Medicaid director said that 120 retarded persons had been transferred to smaller community settings and day treatment programs. He said that another 45 group homes are expected to open in fiscal year 1987, with 255 more retarded nursing home residents being transferred.

HCFA's March 1986 report also provided details on problems identified in the plan of care of retarded residents at the two nursing homes visited. At one home, which had a mental retardation specialist as a consultant, HCFA found that the active treatment plans of care in the medical records were inadequate because they did not address active treatment methods or establish measurable goals in terms of patient development and progress. HCFA found that the active treatment plans of care at the second nursing home, which had a mental retardation specialist work with retarded residents 2 or 3 times a month, were "sparse" and did not set forth measurable goals. HCFA attributed the problems to a lack of understanding of what goes into an active treatment plan and recommended that staff in nursing homes that accept retarded residents be trained in what constitutes an active treatment plan and how to measure each resident's progress and development against the goals in the plan.

HCFA Revises Manual

In an August 1986, revision to the State Medicaid Manual, HCFA expressed concern that many of the retarded persons in nursing homes are not receiving the developmental services they need because they were inappropriately placed in the nursing homes. The revision states that the developmental needs of mentally retarded persons place a particularly compelling responsibility on the facilities and the inspection teams reviewing the adequacy of the services provided to individual residents (the inspection of care) and the capability of the nursing home to provide quality care (the facility inspection) to assure that the placement of such individuals is appropriate and that needed services are, in fact, delivered.

The State Medicaid Manual revision reemphasized HCFA's position that a mentally retarded person whose primary need is for active treatment should be placed in an intermediate care facility for the mentally retarded. It states that only a small percentage of mentally retarded persons would appropriately be placed in skilled nursing facilities, but reemphasizes that even when the primary needs of retarded persons in skilled nursing facilities are medical, their developmental needs must still be met by the facility to the extent allowed by the individual's physical condition.

According to the manual revision, a patient well enough to attend outside training would almost always be well enough to be placed in an intermediate care facility for the mentally retarded or other appropriate setting. It says, however, that another small group of mentally retarded individuals that may be appropriately placed in an intermediate care facility would include those of advanced age for whom developmental training is no longer appropriate. The manual revision cautions, however, that this decision must be made on an individual basis rather than at an arbitrary age because some elderly retarded persons benefit greatly from continued developmental services.

Finally, the manual revision warns that failure to comply with the requirements for appropriate placement of mentally retarded persons in nursing homes could affect federal funding.

The manual revision establishes expectations with respect to the placement of and services to be provided to the mentally retarded in nursing homes, but does not establish additional program controls to help ensure that those expectations are met.

Conclusions

Many mentally retarded persons in nursing homes could benefit from active treatment to develop to their full potential. Adequate program controls do not exist, however, to ensure that those needs are identified and met in the most appropriate care settings. Program controls established in Indiana and Illinois in response to studies by HCFA's Chicago regional office provide a framework for actions by other HCFA regions and states. HHS should amend Medicaid regulations to require states to specify the role of nursing homes in the state's program for the mentally retarded and the roles of retardation agencies in addressing the needs of retarded nursing home residents. In addition, HHS should establish plan-of-care and inspection-of-care requirements similar to those for intermediate care facilities for the mentally retarded.

Recommendations

We recommend that the Secretary of HHS direct the Administrator of HCFA to require states that have not already done so to identify the mentally retarded currently in nursing homes, assess their active treatment needs, and develop programs to meet their needs.

We also recommend that the Secretary revise Medicaid regulations to require:

- Nursing homes to specifically address active treatment in plans of care for their retarded residents.
- Inspection-of-care teams to assess the active treatment needs and services of mentally retarded nursing home residents.
- States to include a staff member trained in mental retardation on inspection-of-care teams when a nursing home has retarded residents.
- States to develop written procedures outlining the role of nursing homes in the state's program for the mentally retarded.
- States to have the state retardation agency assess the active treatment needs of the mentally retarded and the appropriateness of their nursing home placement.

Agency Comments and Our Evaluation

HHS, Massachusetts, and Connecticut generally agreed with our findings, conclusions, and recommendations and indicated that actions have been or will be taken to better ensure that mentally retarded nursing home residents receive needed active treatment services in the most appropriate setting. Rhode Island officials generally disagreed with our findings and recommendations and indicated that procedures have been established to prevent the inappropriate placement of the mentally retarded in nursing homes and ensure that needed services are provided; but the officials offered conflicting comments on whether a problem existed at the time of our visit. Indiana and Illinois did not provide comments.

HHS Comments

HHS generally agreed with the report's presentation as to content, findings, and related conclusions. Although HHS said that it was equally satisfied with the report's recommendations, it said it could not, at this time, make a definitive statement as to their implementation. According to HHS, extensive coordination and analysis still needs to be completed before a decision can be made as to the propriety of the means for carrying out the suggested revisions to Medicaid regulations. HHS said that such factors as budget implications, recent legislative changes, and state flexibility will all need to be carefully considered before a definitive

position can be taken. An internal working group examining policies related to the financing and delivery of services for mentally retarded and other developmentally disabled people, will, HHS said, consider our report during its deliberations.

Actions taken by Indiana, Illinois, Massachusetts, and Connecticut to establish coordination between the Medicaid and retardation agencies should give HHS a good foundation for developing the recommended revisions to Medicaid regulations.

Massachusetts Comments

Massachusetts said that our report acutely demonstrates the need for the Secretary of HHS to revise Medicaid regulations to clarify state and provider responsibilities in serving the mentally retarded in nursing homes. According to the state, it has established the necessary systems to address the needs of mentally retarded nursing home residents and would welcome the opportunity to work with HHS in revising the regulations.

Massachusetts said that it has been aware of issues concerning the admission and follow-up of mentally retarded persons in nursing homes and has begun a number of initiatives to address these individuals' needs. It said that while these activities are directed primarily at consent decree class members, Massachusetts has begun to address the needs of the non-class members discussed in our report as well.

According to Massachusetts, the Division of Mental Retardation convened a working group representing relevant state agencies and the long-term care provider community that developed a plan for

- meeting the needs of mentally retarded individuals living in nursing homes,
- creating mechanisms to secure needed services, and
- establishing effective communications between providers and relevant state agencies.

Massachusetts said that the Division of Mental Retardation has already implemented a number of actions to improve services to consent decree class members, including the assignment of a service coordinator, the development of a plan of care, administration of a standardized test to

identify service needs, documentation of efforts to obtain needed services, monthly visits to the retarded nursing home residents by the service coordinator, and semiannual contact of any class member who refuses active treatment services.

According to Massachusetts, the information gathered from these activities has enabled the Division of Mental Retardation to compile detailed data on each class member's needs. Massachusetts said that based on these data, it has developed an action plan to develop

- alternative residential options for individuals who do not require nursing home services,
- affiliation agreements between nursing homes and local Division of Mental Retardation offices to provide services not available at the nursing home,
- interagency agreements between relevant state agencies defining the role of each in providing or assuring that needed services are available and appropriately implemented, and
- communications and training relationships between the Division of Mental Retardation and the state Elder Affairs agency and its Ombudsman program.

The actions Massachusetts is taking should better ensure that the active treatment needs of mentally retarded nursing home residents are met.

Connecticut Comments

Connecticut said that people in long-term care facilities make up a substantial portion of the mentally retarded population in the state and that it has initiated a number of interagency efforts to assess and meet the needs of those individuals. According to Connecticut, the Departments of Mental Retardation and Income Maintenance embarked on several interagency cooperative efforts to identify and address the needs of mentally retarded nursing home residents after we completed our work in Connecticut. These efforts, Connecticut said, include

- training staff from the Departments of Mental Retardation and Income Maintenance,
- orienting attending physicians in nursing homes to state agency policies,
- having Department of Mental Retardation staff participate in inspections of care, and

- holding ongoing meetings between the Department of Mental Retardation's long-term care coordinator and the Department of Income Maintenance's chief of long-term care services to coordinate implementation of the interagency agreement.

Connecticut said that it is focusing its efforts on consent decree class members, but that placement planning for the remaining nursing home residents will continue with efforts to support existing placements occurring in the interim.

According to Connecticut, the Department of Mental Retardation believes, in general, that long-term care facilities are not the most appropriate placements for persons with mental retardation. The department's policy prohibits placing any person in a long-term care facility unless it is clearly demonstrated that the person's medical needs override all other needs. Connecticut said that, at this time, no new placements to such facilities occur unless there is "overwhelming agreement" by an interdisciplinary team and an appropriate medical diagnosis.

According to Connecticut, 47 mentally retarded nursing home residents have been transferred to community placements, and another 150 are expected to be placed in the community by the end of June 1989.

Connecticut's planned and ongoing actions should help ensure that the mentally retarded are placed in the most appropriate care setting and that they receive adequate active treatment services.

Connecticut agreed with our recommendations that federal regulations be adopted clarifying the responsibilities of nursing homes to provide active treatment services and suggested that we explore with HCFA the process for obtaining Medicaid reimbursement for active treatment services offered in nursing homes.

The specific payment methods used to reimburse nursing homes under Medicaid are primarily left to the discretion of the states. We believe that HCFA should work with the states in determining the best way to handle reimbursement for active treatment services offered in nursing homes. We would, in turn, be willing to consult with HCFA.

Rhode Island Comments

Rhode Island provided separate comments from its Departments of Health; Human Services; and Mental Health, Retardation, and Hospitals. Officials of all three departments indicated that mentally retarded

nursing home residents in Rhode Island have had their active treatment needs assessed, but offered conflicting comments about whether a problem existed at the time of our visit.

The assistant director, Division of Medical Services, Department of Human Services, concluded that Rhode Island is in compliance with all of the current Medicaid regulations that pertain to the treatment of mentally retarded persons in nursing homes because all of our recommendations request HHS to revise existing Medicaid regulations to impose additional requirements.

As discussed on pages 12 and 27, under current Medicaid regulations, retarded nursing home residents should have their developmental needs met by the facility in the context of the individual's overall physical condition. To the extent that retarded nursing home residents in Rhode Island need active treatment services that they are not now receiving, the state is not in compliance with existing Medicaid regulations.

The assistant director said that our report is directed to only a small portion of Rhode Island's extensive coverage for the mentally retarded. He also said that about 20 percent of the Medicaid expenditures for the state's 1986 fiscal year were expended for services for the mentally retarded.

Our report is not intended to reflect Rhode Island's overall efforts to provide services to the mentally retarded. It focuses only on mentally retarded nursing home residents.

Regarding our recommendation that HHS require states to assess the active treatment needs of the mentally retarded currently in nursing homes and develop programs and/or alternative placements to meet their needs, the assistant director said that the state has assessed the active treatment needs of the 213 mentally retarded residents in nursing homes and has assured that they are receiving active treatment appropriate to their condition.

We noted on page 23 that the Rhode Island retardation agency had assessed the active treatment day program needs of 97 nursing home residents we identified as needing such an assessment. The agency had not, however, performed a detailed multidisciplinary evaluation of the residents or evaluated their need for support services, such as behavioral counseling and physical, speech, and occupational therapy. Accordingly, HHS should determine the adequacy of the assessments performed.

According to the executive director, Division of Retardation, Department of Mental Health, Retardation, and Hospitals, no person with retardation is ever placed in a nursing home without full review by his office and conversations with staff of the Department of Human Services and staff of the Division of Retardation. The comments provided by the assistant director, Division of Medical Services, Department of Human Services, state that "since most of the 213 mentally retarded persons in Rhode Island nursing homes identified by the GAO were placed prior to June of 1984, they were not known to the Retardation Agency." In an August 1986 memorandum, a Division of Retardation casework supervisor notified the executive director that he had "contacted or visited" the nursing homes in our review "in which we [Division of Retardation] had no record of the [GAO] identified clients."

According to the assistant director, Division of Medical Services, the Rhode Island Medicaid agency has consulted with the Division of Retardation before authorizing nursing home placement for retarded persons since June 1984. The retardation agency is, he said, now aware of all current admissions of retarded persons to nursing homes.

While the June 1984 action should help prevent inappropriate placement of the mentally retarded in nursing homes, it is not, in our opinion, adequate to determine whether those retarded persons placed in nursing homes because of their medical conditions have their active treatment needs assessed. The assistant administrator for long term care previously told us that there are no referrals if the retarded person's medical diagnosis warrants nursing home admission.

As stated on page 28, even when the primary needs of retarded persons in skilled nursing facilities are medical, their developmental needs must still be met by the facility to the extent allowed by the individual's physical condition. Accordingly, we continue to believe that Rhode Island should establish procedures for assessing the active treatment needs of mentally retarded nursing home residents similar to the actions outlined by Massachusetts and Connecticut.

The executive director, Division of Retardation, said that persons with mental retardation are placed in nursing homes only if their medical condition warrants such placement, irrespective of their level of retardation. Similarly, he said that Rhode Island does not now dump, nor has it ever dumped, retarded persons in nursing homes.

We did not evaluate, and did not question, whether the retarded individuals in Rhode Island's nursing homes have medical conditions that warrant their nursing home placement. Our review focused on whether mentally retarded nursing home residents had had their active treatment needs assessed. This issue was not addressed by the executive director.

The executive director also suggested that we review our data and be very clear about who we are calling retarded and who is actually retarded. We relied on state records to identify nursing home residents with a diagnosis of retardation. As noted on page 23, the Division of Retardation confirmed the diagnosis of 79 of the 97 nursing home residents it assessed. The "inappropriate" diagnoses of the other 18 nursing home residents were made not by our auditors, but by psychiatric hospitals, which use a different diagnosis of retardation than that used by the retardation agency.

The chief of Rhode Island's Division of Facilities Regulation, Department of Health, disagreed with our finding that inspections of care were inadequate. He said that each of the social workers on the inspection-of-care teams has had extensive experience not only in the problems of the elderly but also with the mentally retarded. The chief agreed that the inspection-of-care teams did not review active treatment needs of mentally retarded nursing home residents as they would in an intermediate care facility for the mentally retarded, but said that team members are mindful of active treatment and, as appropriate, have requested an inspection-of-care team for the mentally retarded to review such residents. Finally, he said that physical, speech, and occupational therapy and behavioral counseling are services that are routinely reviewed by inspection-of-care teams in facilities for the mentally retarded as well as other nursing homes to determine residents' needs. According to the chief, had any of the mentally retarded residents required these services, they would have been identified in the inspection of care and reported to the Medicaid agency.

In initial discussions with us, the chief had indicated that inspection-of-care team members had received no training on the needs of the mentally retarded. In a later meeting, he identified several inspection-of-care team members who had previously worked in the Division of Mental Retardation.

As discussed on pages 23 and 24, when Rhode Island retardation agency staff assessed and reached conclusions on the active treatment day program needs of 97 nursing home residents who needed such an assessment, the agency identified 10 residents who needed and wanted day programs who were not receiving such services. Another 25 were identified as needing but not wanting active treatment. The inspections of care for the 35 residents did not identify their active treatment needs, suggesting that either the inspection-of-care staff were not adequately trained to assess the special needs of the retarded or the inspections of care were not thorough enough to identify those needs.

Because the retardation agency did not assess the 97 retarded residents' needs for speech, physical, and occupational therapy or behavioral counseling, we cannot comment on the accuracy of the inspection agency chief's contention that any retarded residents needing such services would have been identified in the inspection of care. However, based on the problems in identifying day programming needs of retarded nursing home residents, we continue to believe that the inspection agency should provide training in the needs of the retarded to inspection-of-care teams and assess each retarded nursing home resident using a form designed to evaluate the needs of mentally retarded residents.

With respect to the chief's comment that team members have, as appropriate, requested an inspection-of-care team for the mentally retarded to review mentally retarded nursing home residents, we note that the chief had previously told two of our staff members that during his 29 years with the agency, he did not recall a recommendation for day treatment having been made.

According to the executive director, Division of Mental Retardation, Department of Health surveyors review all retarded nursing home residents annually. He said that whenever it is ascertained that a person with retardation no longer requires the services of a nursing home, a recommendation is made to his office and the Department of Human Services and action is taken to place the person in a more appropriate setting.

As discussed above, the primary issue is not whether retarded nursing home residents in Rhode Island are appropriately placed in nursing homes but whether they are receiving appropriate active treatment services for their retardation. While we agree that retarded nursing home residents who no longer require nursing home placement for their medical conditions should be moved to a more appropriate care setting, it is

equally important that retarded individuals who remain in nursing homes for medical reasons receive active treatment services to the extent permitted by their medical conditions. None of the actions described by the executive director address active treatment services for such retarded residents—the individuals discussed in this report.

Nursing Homes Visited by GAO in Three States

Nursing home	Level of care[a]	Number of beds	Medicaid patients	Retarded patients	Retardation agency: Monitored	Retardation agency: Provided active treatment	Medical records reviewed	Active treatment provided by nursing home
Aaron Manor Health Care Facility Route 148 Chester, CT 06412	ICF	60	28	2	1	0	2[b]	0
Canterbury Villa of Willimantic 595 Valley Street Willimantic, CT 06226	SNF/ICF	120	88	2	1	0	2[b]	0
Meadows Manor 333 Bidwell Street Manchester, CT 06040	SNF/ICF	518	430	99	73	63	0[c]	0
Mountain View Healthcare 581 Poquonock Avenue Windsor, CT 06095	SNF	120	73	9	8	1	9[b]	0
Connecticut Subtotal	**4**	**818**	**619**	**112**	**83**	**64**	**13**	**0**
Bayview Convalescent Home, Inc. 93 Miantonomi Avenue Newport, RI 02840	ICF	51	25	3	1	1	3[b]	0
Laurel Foster Home, Inc. 51 Laurel Avenue Coventry, RI 02893	ICF	57	44	5	0	0	5[b]	0
Woonsocket Health Centre 262 Poplar Street Woonsocket, RI 02895	SNF/ICF	275	243	5	0	0	5[b]	0
Rhode Island Subtotal	**3**	**383**	**312**	**13**	**1**	**1**	**13**	**0**
Auburn House Nursing Home 9 River Street Jamaica Plains, MA 02130	ICF	71	68	6	1	1	0[b,d]	0
Harvard Manor Nursing Home 273 Harvard Street Cambridge, MA 02139	ICF	95	84	3	0	0	0[b,d]	0
Elm Hill Nursing Home 237 Walnut Avenue Boston, MA 02119	ICF	53	52	11	9	2	11	1
Bartlett Manor Nursing Home 180 Summer Street Malden, MA 02148	ICF	40	39	20	8	1	0	0
Buchanon Nursing Home 190 Summer Street Malden, MA 02148	ICF	35	35	22	6	6	0	0
Robbin House Convalescent Home 205 Elm Street Quincy, MA 02169	SNF/ICF	114	103	14	1	1	14	0

Nursing home	Level of care[a]	Number of beds	Medicaid patients	Retarded patients	Retardation agency		Medical records reviewed	Active treatment provided by nursing home
					Monitored	Provided active treatment		
Greenlawn Nursing Home 14 East Grove Middleborough, MA 02346	ICF	47	47	24	2	0	24	12
Fairhaven Nursing Home 476 Varnum Avenue Lowell, MA 01854	SNF/ICF	166	91	14	2	0	14	0
Massachusetts Subtotal	**8**	**621**	**519**	**114**	**29**	**11**	**63**	**13**
Total	**15**	**1,822**	**1,450**	**239**	**113**	**76**	**89**	**13**

[a]ICF = intermediate care facility, SNF = skilled nursing facility

[b]We observed inspections of care at these homes

[c]We accompanied mental retardation officials to these nursing homes to observe their monitoring activities and did not request access to resident medical records

[d]We accompanied inspectors to these nursing homes but encountered an access to-records problem in Massachusetts

Comments From the Department of Health and Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

FEB 10 1987

Mr. Richard L. Fogel
Assistant Comptroller General
U.S. General Accounting Office
Washington, D.C. 20548

Dear Mr. Fogel:

The Secretary asked that I respond to your request for the Department's comments on your draft report, "Medicaid: Addressing the Needs of Mentally Retarded Nursing Home Residents."

The Department has reviewed the report and would like to point out that it generally agrees with the report's presentation as to content, findings and related conclusions. However, while the Department is equally satisfied with the report's recommendations, it cannot make a definitive statement, at this time, as to their ultimate implementation. As you are aware, because the majority of those recommendations call for revisions to regulations, a great deal of extensive coordination and analysis still needs to be completed before a decision can be made as to the propriety of the means for carrying out the suggested revisions. Factors such as budget implications, recent legislative changes and State flexibility will all need to be carefully considered before a definitive position can be taken. The Department has an internal working group examining policies related to the financing and delivery of services for mentally retarded and other developmentally disabled people. The working group will consider the draft report during its deliberations.

We appreciate the opportunity to comment on this draft report before its publication and over the next several months the Department will be giving every consideration as to the disposition of the reported recommendations.

Sincerely yours,

Richard P. Kusserow
Inspector General

Comments From the Commonwealth of Massachusetts

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One Ashburton Place, Room 1109
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MICHAEL S DUKAKIS
GOVERNOR
PHILIP W JOHNSTON
SECRETARY

February 10. 1987

Mr. Richard L. Fogel
Assistant Comptroller General
U.S. General Accounting Office
Washington, D.C. 20548

Dear Mr. Fogel:

The Governor has asked me to provide you with comments on the G.A.O. report of services provided to mentally retarded persons living in nursing homes.

Massachusetts has been aware of issues concerning the admission and subsequent follow-up of mentally retarded persons in nursing homes. Many of these past admissions were individuals protected by consent decrees, referred to as class members. As a result of this protection, we have begun a number of initiatives to address the needs of these individuals.

The Division of Mental Retardation (DMR) has convened a working group of people representing relevant state agencies and the long term care provider community. The group has developed a plan for:

- meeting the needs of mentally retarded individuals living in nursing homes;
- creating mechanisms in existing regulatory and case management systems to secure needed services; and
- establishing effective communications between providers and relevant state agencies.

The DMR has already implemented a number of activities for class members living in nursing homes. For each class member DMH has required:

- the assignment of a service coordinator;
- development of a full Individual Service Plan (ISP);

- the administration of a current Massachusetts Service Coordination Battery (MSCB);
- the documentation of efforts to obtain needed services;
- monthly visits by the service coordinator; and
- semi-annual contact for any class member who refuses services from DMR.

With the information gathered from the above activities, DMH has compiled detailed data on each individual class member's needs. This has been translated into action steps to accomplish the following:

1. Develop alternative residential options for individuals who do not require nursing home services.
2. Develop affiliation agreements between nursing homes and local DMR offices to provide services not available at the nursing home.
3. Develop interagency agreements between relevant state agencies defining the role of each in providing or assuring that needed services are available and appropriately implemented.
4. Develop communication and training relationships between the DMR and the state Elder Affairs agency and its Ombudsman program.

While the above described activities are directed primarily at class members, we have begun to address the needs of non-class members as well. This is the group of individuals to which the G.A.O. report refers.

We believe we have established the necessary systems to address the needs of mentally retarded nursing homes. We welcome the opportunity to work with the Secretary on revising Medicaid regulations which would clarify state and provider responsibilities in serving these people. The G.A.O. report acutely demonstrates the need for this to happen.

Sincerely,

Philip W. Johnston
Secretary

PWJ:rag

cc: Mary McCarthy, Deputy Commissioner

Comments From the State of Connecticut

STATE OF CONNECTICUT
DEPARTMENT OF MENTAL RETARDATION

OFFICE OF THE
COMMISSIONER

February 11, 1987

Mr. Richard L. Fogel
Assistant Comptroller General
United States
General Accounting Office
Washington, D.C. 20548

Dear Mr. Fogel:

Thank you for giving Connecticut the opportunity to respond to the draft report addressing the needs of nursing home residents with mental retardation.

Governor William O'Neill has asked that we respond to your report and assure you that both departments recognize the needs of people in long-term care facilities and have initiated a number of interagency efforts to assess and meet the needs of these individuals.

We concur with the GAO recommendations that federal regulations be adopted clarifying the responsibilities of nursing facilities to provide habilitative services. Further, we suggest that the GAO specifically explore with HCFA the process for obtaining Medicaid reimbursement for habilitative services offered in nursing homes.

The Department of Mental Retardation believes, in general, that long term care facilities are not the most appropriate placements for persons with mental retardation. DMR policy prohibits placement of any person in a long-term care facility unless it is clearly demonstrated that the person's medical needs override all other program needs. At this time, no new placements to such facilities are to occur unless there is overwhelming agreement by the interdisciplinary team and an appropriate medical diagnosis. In the past eighteen months, forty-seven (47) of the DMR clients in nursing facilities have been transferred to community placements. These placement initiatives are continuing and we expect to place an additional 150 nursing home residents who are mentally retarded by the end of June, 1989.

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Mr. Richard L. Fogel
Page 2
February 11, 1987

As documented in your report, efforts have been made to provide habilitative services to mentally retarded nursing home residents of nursing facilities. Subsequent to your inspections in Connecticut, the Departments of Mental Retardation and Income Maintenance have embarked on several important interagency cooperative efforts to identify and address the needs of people with mental retardation in long-term care. Some of those efforts include:

a. Training of DMR case managers, clinical support staff, and DIM IPR/UR teams in numerous areas, including:

- tardive dyskinesia screening
- feeding
- positioning
- adaptive equipment
- use of restraints
- psychotropic medication

b. An orientation to state agency policies for attending physicians within nursing home facilities.

c. Participation of DMR staff on DIM's IPR/UR teams to assess compliance with state agency policies, specifically around use of psychotropic medication and restraint.

d. Ongoing meetings between the DMR long-term care coordinator and the DIM chief of long-term care services to coordinate implementation of the interagency agreement.

At the present time these efforts are being focused on CARC v. Thorne class members. Placement planning for the remaining long-term care residents will continue with efforts to support existing placements occurring in the interim.

Mr Richard L Fogel
Page 3
February 11, 1987

The Department of Mental Retardation's overall deinstitutionalization strategy is comprehensive and is based on its mission of joining with others to create conditions under which people with mental retardation experience:

Presence and participation in Connecticut town life

Opportunities to develop competence

Opportunities to make choices in the pursuit of a personal future

Good relationships with family members and friends

Respect and dignity

We recognize the need to make this mission apply to all people with mental retardation in the state regardless of where they reside. People in long-term care facilities make up a substantial portion of this population, and their needs are being addressed with great care and concern

Brian R. Lensink
Commissioner
Dept. of Mental Retardation

Stephen B. Heintz
Commissioner
Dept. of Income Maintenance

Comments From the State of Rhode Island

STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

Department of Human Services
DIVISION OF MEDICAL SERVICES
600 New London Avenue
Cranston, Rhode Island 02920

February 12, 1987

Mr. Richard L. Fogel
Assistant Comptroller General
United States General Accounting Office
Washington, D.C. 20548

Dear Mr. Fogel:

This is in response to your letter of December 30, 1986, requesting comments relative to the General Accounting Office's proposed report to the Secretary of Health and Human Services on the results of the review of services provided to mentally retarded persons living in nursing homes other than Intermediate Care Facilities for the Mentally Retarded. Also enclosed are comments from the Rhode Island Department of Health and the Department of Mental Health, Retardation and Hospitals.

It should be noted that all of the report's recommendations request the Secretary of Health and Human Services to revise existing Medicaid regulations to impose additional requirements in this area. We therefore must conclude that the State of Rhode Island is in compliance with all of the present regulations that pertain to the treatment of mentally retarded persons in Skilled Nursing and Intermediate Care Facilities.

Additionally, GAO is recommending that the Secretary of Health and Human Services require those states that have not already done so to assess the active treatment needs of the mentally retarded currently in nursing homes and develop programs and/or alternative placements to meet their needs. Please be advised that the State of Rhode Island has assessed the active treatment needs of the mentally retarded in nursing homes and has assured that these 213 individuals are receiving active treatment appropriate to their condition.

Additionally, since June of 1984, the Rhode Island Medicaid Agency has consulted with the Division of Retardation before authorizing placement for retarded persons in Skilled Nursing and Intermediate Care Facilities. Since most of the 213 mentally retarded persons in Rhode Island nursing homes identified by the GAO study were placed prior to June of 1984, they were not known to the Retardation Agency. However, the Retardation Agency is now aware of all current admissions of retarded persons to Skilled Nursing and Intermediate Care Facilities. It should be noted that of the 1,477 mentally retarded nursing home residents that the report cites as not being known to the Medicaid Agencies in Massachusetts, Connecticut, and Rhode Island, only 131 of these were in the State of Rhode Island.

We wish to point out that in Rhode Island approximately 600 persons are in privately-operated Intermediate Care Facilities for the Mentally Retarded and another

47

400 in publicly-operated Intermediate Care Facilities for the Mentally Retarded; whereas, only approximately 200 retarded people are in general nursing homes.

Unfortunately, the report is directed to only a small portion of Rhode Island's extensive coverage for the mentally retarded through the Medicaid program with no identification of the fact that some 700 persons are served in approximately 100 group homes located in residential areas throughout the State, licensed and certified as Intermediate Care Facilities for the Mentally Retarded serving from four to fifteen persons per home. Approximately, $56,000,000, 20 per cent, of the Medicaid expenditures for the 1986 State fiscal year were expended for services for the mentally retarded.

Sincerely,

Anthony Barile
Assistant Director

AB/amd

Enclosures

STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

Department of Mental Health, Retardation and Hospitals
DIVISION OF RETARDATION
600 New London Avenue
Cranston, R.I. 02920

February 12, 1987

Richard J. Fogel
Assistant Comptroller General
United States General Accounting Office
Washington, D. C. 20548

Dear Mr. Fogel:

I am in receipt of a draft of a proposed report from your office regarding "MEDICAID: Addressing the Needs of Mentally Retarded Nursing Home Residents (101102)." This draft was forwarded to Governor DiPrete for review and comment.

Frankly, the report is so inadequate and erroneous that I am not sure exactly where to start. First, I would like to suggest that the person who prepared the report either purposefully, or through carelessness or inexperience, did not represent appropriately in the report that information which was provided to them by state officials in Rhode Island. We attempted to correct the errors in this information in face to face conversations, to no avail.

As a person who has been operating retardation services in Rhode Island and in other states for the past twenty years, and who has served as a consultant, both to state and private agencies and to the United States Department of Justice and to numerous Federal Courts, specifically on the issue of persons with retardation who reside in nursing homes and other long term nursing facilities, I take strong exception to the results of this purported study. In Rhode Island, no person with retardation is ever placed into a nursing home without full review by my office and conversations

page 2.

with staff of the Department of Human Services and staff of the Division of Retardation. In addition, all persons with retardation who are placed in nursing homes are only placed in nursing homes if their medical condition warrants such placement, irrespective of their level of retardation. The Department of Health surveyors review all such persons on an annual basis, and whenever it is ascertained that a person with retardation no longer requires the services of a nursing home, then a recommendation is made to my office and the Department of Human Services. More importantly, action is taken to place the person in a more appropriate setting. I suggest that it would be more purposeful for your surveyors to take a look at the confusion and chaos that emanates from the various HCFA offices throughout the country as they take action to try to force people out of ICF/MRs and into nursing care facilities because it is cheaper. I further suggest that your surveyors review their data and be very clear about who they are calling retarded and who is actually retarded.

I believe that your draft report unfairly and inappropriately misrepresents the quality of work that so many state professionals in Rhode Island have striven to achieve. We do not now, nor have we ever, dumped retarded persons into nursing homes. We have been heavily criticized by HCFA because we have refused to use nursing homes inappropriately. Your report does not alter the truth. It merely misrepresents the actual service activity in the State of RHode Island. I request that you take a closer and more professional look in Rhode Island.

Sincerely,

Robert L. Carl, Jr., Ph.D.
Executive Director

RLC/ael

State of Rhode Island and Providence Plantations

Department of Health
CANNON BUILDING
Davis Street
Providence, R.I. 02908

11 February 1987

Mr. Richard L. Fogel
Assistant Comptroller General
U.S. General Accounting Office
Washington, DC 20548

Dear Mr. Fogel:

Now on pp 21-22

We appreciate the opportunity to comment upon the draft of a proposed report on mentally retarded residents of nursing homes. This agency has confined its comments to those issues raised on pages 23 - 26 regarding the Inspections of Care.

The report alleges that the Inspections of Care were inadequate because they:

1. were not performed by persons trained in mental retardation;

2. did not determine whether the active treatment needs of the mentally retarded had been identified; and

3. did not determine whether the services available in the nursing home were adequate to meet the residents treatment needs.

We believe this finding in incorrect for Rhode Island's program. Each of the social workers on the Inspection of Care teams has had extensive experience not only in the problems of the elderly but also with the mentally retarded. This fact was brought out with the GAO auditors and, again, at the exit conference. Inspection of Care teams did not review active treatment needs of mentally retarded residents as they would in an ICF/MR; however team members are mindful of active treatment and, as appropriate, have requested an Inspection of Care team for the mentally retarded to review such residents. Physical, speech and occupational therapy and behavioral counselling are all services that are routinely reviewed by Inspection of Care teams in facilities for the mentally retarded as well as SNF's and general ICF's to determine resident needs. Had any of the mentally retarded residents required these services, they would have been identified in the Inspection of Care and reported to the medicaid agency.

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In general, we believe the report presents conditions in the three states as though they were identical when, in fact, they are very dissimilar. This is a disservice to all three states.

Sincerely,

Robert D. DiCenso, Chief
Division of Facilities Regulation

llp

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